Health-related quality of life in young survivors of childhood cancer

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Abstract: PURPOSE Childhood cancer and its treatment may affect health-related quality of life (HRQoL) in childhood cancer survivors, but population-based studies in young survivors are scarce. We aimed to: (1) compare HRQoL between young survivors and population norms and (2) find factors that influence parent-reported HRQoL in survivors. METHODS As part of the Swiss Childhood Cancer Survivor Study, a questionnaire was mailed to parents of survivors aged 8-16 years, registered in the Swiss Childhood Cancer Registry, 5 years after diagnosis. We used the KIDSCREEN-27 instrument to compare self- and parent-reported HRQoL between survivors (N = 425) and standardized norms in the five dimensions of physical well-being, psychological well-being, autonomy, peers and school environment (mean = 50, SD = 10). We then used multivariable linear regressions to test the influence of socio-demographic and cancer-related factors on HRQoL. RESULTS Self-reported physical well-being was comparable to norms. Other HRQoL dimensions were higher than norms, with the highest mean = 52.2 ($p < 0.001$) for school environment. Parent-reported HRQoL in survivors was comparable to population norms; only physical well-being was lower (mean = 47.1, $p < 0.001$), and school environment was higher (mean = 51.1, $p = 0.035$). Parent-reported HRQoL was lower for survivors of CNS tumors (physical well-being: = -5.27, $p = 0.007$; psychological well-being: = -4.39, $p = 0.044$; peers = -5.17, $p = 0.028$), survivors of neuroblastoma (psychological well-being = -5.20, $p = 0.047$), and survivors who had had a relapse (physical well-being = -5.41, $p = 0.005$). CONCLUSIONS Assessing HRQoL during follow-up care, with a focus on physical well-being, specific diagnoses (e.g., CNS tumor) and late complications (e.g., relapse) might help to early identify problems and offer support to survivors with reduced HRQoL.

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Information Needs in Parents of Long-Term Childhood Cancer Survivors

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Background. Parents' knowledge about cancer, treatment, potential late effects and necessary follow-up is important to reassure themselves and motivate their child to participate in regular follow-up. We aimed to describe (i) parents' perception of information received during and after treatment; (ii) parents' current needs for information today, and to investigate; and (iii) associations between information needs and socio-demographic and clinical characteristics. ***Methods.*** As part of the Swiss Childhood Cancer Survivor Study, a follow-up questionnaire was sent to parents of survivors, diagnosed < 16 years and after 1990, and aged 11–17 years at study. We assessed parents' perception of information received and information needs, concerns about consequences of the cancer and socio-demographic information. Information on clinical data was available from the Swiss Childhood Cancer Registry. ***Results.*** Of 309 eligible parents, 189 responded (67%; mean time since diagnosis: 11.3 years, SD = 2.5). Parents perceived to have received verbal information (on illness: verbal 91%, written 40%; treatment: verbal 88%, written 46%; follow-up: verbal 85% written 27%; late effects: verbal 75%, written 19%). Many parents reported current information needs, especially on late effects (71%). The preferred source was written general (28%) or verbal information (25%), less favored was online information (12%). Information needs were associated with migration background ($P = 0.039$), greater concerns about consequences of cancer ($P = 0.024$) and no information received ($P = 0.035$). ***Conclusion.*** Parents reported that they received mainly verbal information. However, they still needed further information especially about possible late effects. Individual long-term follow-up plans, including a treatment summary, should be provided to each survivor, preferably in written format. Pediatr Blood Cancer

Key words: follow-up care; information needs; information received; parents of childhood cancer survivors; pediatric oncology; questionnaire survey

INTRODUCTION

Childhood cancer survivors are at considerable risk of late effects [1], requiring their parents to be informed about recommended follow-up care or screening in order to make appropriate decisions and give support to their child [2]. Parents' knowledge about diagnosis, treatment administered, appropriate long-term care plan and risk for late effects is important to understand the disease and provide reassurance. Parents are the child's guardian because the child is often very young at diagnosis. They therefore play a central role in subsequently transferring knowledge and information to their child and thus empowering participation in follow-up care [3].

Adequate information for parents of chronically ill children is not only important for knowledge transfer to their child but also for parents themselves to feel reassured and less worried [4]. Many parents of children with cancer desire an "end of treatment meeting" [5], which could help to reduce their concerns about recurrence, and treatment late effects and inform them about appropriate follow-up care recommendations. A review on communication practices in other chronic diseases concluded that parental stress and anxiety can be reduced with improved education and communication to parents in newborn screening programs [6].

A recent study among parents of childhood cancer patients shortly after diagnosis showed their satisfaction with information on current disease and treatment, but they also reported a lack of information about the future [7]. This lack of information might increase with time after diagnosis and fewer health care visits during follow-up. Another study showed that shortly after the end of treatment survivors are generally satisfied with the information received [8]. However, parents were interested in receiving additional information on various topics such as how to prepare for and cope with the end of treatment. A recent Dutch study found that even after a visit to an outpatient clinic, both cancer survivors and their parents still had information needs on late effects and

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Abbreviations: CI, confidence interval; CNS, central nervous system; OR, odds ratio; SCT, stem cell transplantation; SCCR, Swiss Childhood Cancer Registry; SCCSS, Swiss Childhood Cancer Survivor Study; SD, standard deviation; SPOG, Swiss Paediatric Oncology Group

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authors suggested that they might profit from an online platform [9,10]. A study from our group on long-term childhood cancer survivors showed that survivors desired to be better informed especially on potential late effects, and wished to receive personalized information [11].

The literature so far included mainly studies performed shortly after treatment [5,8,12] or focused on information needs of survivors and rarely of the parents [9–11]. We therefore aimed to (i) describe the information parents remembered to have received during and after their child's cancer treatment; (ii) investigate parents' needs for information today many years after diagnosis; and (iii) investigate the association between information needs and (1) parents' socio-demographic characteristics and (2) clinical characteristics of the child's disease.

METHODS

Sample and Procedure

The Swiss Childhood Cancer Registry (SCCR) is a population-based registry including all cancer patients younger than 21 years and Swiss residents at diagnosis who were diagnosed with leukemia, lymphoma, CNS tumor, malignant solid tumor or Langerhans cell histiocytosis [13,14]. The Swiss Childhood Cancer Survivor Study (SCCSS) is a nationwide, long-term survey including a baseline (years 2007–2011) and a follow-up questionnaire (years 2010–2012). The baseline questionnaire included all patients registered in the SCCR who survived at least 5 years and were diagnosed between 1976–2005, aged < 16 years [15]. Parents of survivors were contacted if survivors were aged 5–15 years at the time of study. As part of the follow-up survey, parents were contacted again. They were included if they had previously completed the baseline questionnaire, their child or adolescence who survived cancer was aged 11–17 years at study and diagnosed after 1990 (N = 306; Supplemental Figure 1). Some survivors were already aged 18 years by the time the questionnaire was completed by parents.

Among eligible parents, the mother or father who completed the baseline questionnaire was contacted and received a further questionnaire with a different focus and a prepaid return envelope. If they did not reply within 2 months, non-responders received the questionnaire a second time with a reminder letter and another prepaid return envelope. Questionnaires were available in German and French. Ethics approval was provided through the general cancer registry permission of the SCCR (The Swiss Federal Commission of Experts for Professional Secrecy in Medical Research). Additionally, we received a non-obstat statement from the ethics committee of the canton of Bern declaring that the ethics committee did not object to the running of the study.

MEASUREMENTS

Information Received

Parents could indicate whether they remembered having received information from a medical doctor on illness, treatment, follow-up and late effects (perceived of information received: ever/never). For each domain, they could specify the information format: verbal and/or written information, or no information.

Information Needs

Parents could indicate their current information needs in the following domains: illness, treatment, follow-up and late effects (yes/no?). They were asked for each domain to describe the preferred format: (i) verbal; (ii) general written; (iii) personal written; (iv) general online information; or (v) if no information was desired.

Explanatory Variables Assessed by Questionnaire of Parents

We assessed parents' gender, age at study, migration background, language region, parents' education and employment status, their involvement in follow-up care of their child and concerns about the consequences of the child's cancer. Parents' age at study was divided in two categories: ≤ 45 years and > 45 years. Parents were classified as having a migration background if they were not Swiss citizens since birth or not born in Switzerland. Language region was divided into German and French. Parents' education was divided into three categories: primary (compulsory schooling, vocational training); secondary (including teachers, technical, commercial schools etc. and university of applied sciences); tertiary (university) [16]. Employment status was coded as employed (yes/no). Parents were asked whether they were involved in follow-up care of their child (yes/no). Concerns of parents about consequences of their child's illness were assessed by the question "How concerned are you about consequences of your child's illness?" This is an adapted question from the Brief Illness Perception Questionnaire (IPQ) using a 0-to-10 response scale [17]. Items were scored as 0–2 = no concern, 3–6 = medium concerns and 7–10 = high concerns. Throughout the manuscript, this expression will be used as "consequences of cancer." From the baseline questionnaire of the SCCSS, we extracted information about child late effects (yes/no) [15].

Child Clinical Variables Extracted From the SCCR

We extracted medical information on diagnosis and treatment of the child from the Swiss Childhood Cancer Registry: cancer diagnosis, cancer treatment, type of treating hospital, age at diagnosis, time since diagnosis and relapse.

We classified diagnosis according to the International Classification of Childhood Cancer-3rd Edition [18]. For the regression model, we grouped diagnosis into three categories: leukemia/lymphoma, tumors of the central nervous system (CNS) and other tumors. Treatment was coded as: chemotherapy (without radiotherapy but possibly with surgery), surgery only, radiotherapy (with surgery or chemotherapy), and stem cell transplantation (SCT). The type of treating hospital was divided into university and regional hospital. Age at diagnosis was divided into three age categories: 0–1 year, 2–4 years and ≥ 5 years. Time since diagnosis was divided into two categories: 5–10 years and ≥ 10 years. Relapse was coded yes or no.

Analyses

Analyses were conducted using STATA 13.1. First, we describe the study population and differences between participants and non-participants, using proportions, means, chi square statistics and paired *t*-tests. For aims 1 and 2, we summarize proportions with

95% confidence intervals (CI) of parents reporting they received information and their information needs, respectively for the four domains illness, treatment, follow-up and late effects. We describe the type of information they remember to have received and what type of information they would now want. For the descriptive analysis, each domain and format were analyzed separately. For the analytic analysis, we additionally created an overall binary variable: information received (if either verbal or written information was perceived to be received in all four domains) versus no information received (if no information was received in any of the four domains). Additionally, we created a binary variable for each domain of information needs: information needs (if needs were present in at least one format in the respective domain) versus no information needs (no information was desired). For aim 3, we used univariable logistic regression models to analyze associations of socio-demographic characteristics of the parents and clinical factors of the child with information needs. For the analysis, an overall binary variable was created: parents were categorized as having information needs if they reported a need in any of the four domains and as having no needs if they reported no information needs in all four domains. Given the small number of participants we could not perform a multivariable logistic regression model.

RESULTS

Study Population

Of the 306 eligible parents, we traced and contacted 284 (Supplemental Figure 2). Of those, 189 (67%) responded. The mean age of the parents was 46.1 years (SD = 4.8, range 33.5–59.5 years), mean time since diagnosis 11.3 years (SD = 2.5, range 6.8–17.2) and mean age of the child at study completion was 14.7 years (SD = 1.8, range 10.7–18.0 years; Table I). Most children were diagnosed with leukemia (39.2%), followed by CNS tumors (18.0%) and lymphomas (8.5%). There was no difference between participating and non-participating parents regarding language region of Switzerland, cancer type, treatment received, type of treating hospital, child's age at diagnosis, time since diagnosis, relapse status and parent-reported late effects.

Perception of Information Received on Illness, Treatment, Follow-Up and Late Effects

Most parents reported they received information and only a few parents reported not having received any information on one of the domains (Figure 1). Most of the parents who received information had received verbal information (74.6–91.0%). Fewer parents had received written information on illness (39.6%, CI 32.6–46.7%) and treatment (45.5%, CI 38.3–52.7%), and even fewer on follow-up (27.0%, CI 20.6–33.4%) and late effects (19.0%, CI 13.4–24.7%). Of those parents who did not receive information, five (2.6%) reported they received no information on illness, three (1.5%) on treatment, 11 (5.8%) on follow-up and 32 (16.9%) on late effects. Only one parent reported not having received any information on any domain.

Reported Information Needs on Illness, Treatment, Follow-Up and Late Effects

Overall, about half of the parents reported information needs on illness (49.4%, CI 42.0–56.9%), treatment (48.8%, CI 41.3–56.4%) and follow-up (56.6%, CI 49.2–64.0%) irrespective of the format (Figure 2). In contrast, 70.9% (CI 64.0–77.7%) reported information needs on late effects. Across all domains, 45 (23.8%) parents reported no needs in any format. Having or not having information needs was independent of the information received and the format of the information received (written or verbal; Supplemental Table I). Most parents who did not receive any information reported current information needs.

The format most frequently chosen was written general (17.5–27.5%) or verbal (15.9–24.9%) (Figure 3). The format chosen by fewest parents was online information (5.3–12.2%).

Factors Associated With Information Needs

In univariable regression models, parents reporting *overall* information needs were more likely to have a migration background (OR 5.55, CI 0.71–43.2, $P = 0.039$), report concerns about consequences of cancer (medium: OR 2.50; CI 1.04–6.04; high: OR 2.95, CI 1.3–6.68, global p for concerns = 0.024) and did not receive all the information (OR 2.95, CI 0.97–8.90, $P = 0.035$; Table II).

Parents reporting information needs on *illness* were more likely to report greater concerns about consequences of cancer (medium: OR = 2.42, CI 1.07–5.48, high: OR = 2.84, CI 1.34–6.0; global p for concerns = 0.017; Supplemental Table II). Parents reporting information needs on *treatment* were more likely to have a child diagnosed with CNS tumor (OR = 2.88, CI 1.12–6.71) or other tumors (OR = 1.44, CI 0.73–2.83; global p for diagnosis = 0.043) and to report greater concerns about consequences of cancer (medium: OR = 2.04, CI 0.91–4.58; high: OR = 2.47, CI 1.17–5.21, global p for concerns = 0.050). Parents reporting information needs on *follow-up* were more likely to be involved in follow-up care (OR = 2.1, CI 0.99–4.43, $P = 0.049$) and to report greater concerns about consequences of cancer (medium: OR = 2.42, CI 1.07–5.47; high: OR = 3.16, CI 1.49–6.72, global p for concerns = 0.008). Parents reporting information needs on *late effects* were more likely to report late effects (OR = 2.95, CI 1.29–4.88, $P = 0.016$), greater concerns about consequences of cancer (medium: OR = 2.11, CI 0.91–4.88, high: OR = 3.06, CI 1.37–6.84; global p for concerns = 0.019) and did not receive all the information (OR = 2.62, CI 0.95–7.24, $P = 0.045$).

DISCUSSION

A large proportion of parents reported that they received verbal information on illness, treatment and follow-up. While one fifth reported not having received information on late effects, more than half of parents desired more information in a written general or verbal personal way especially about late effects. Information provision through online sources was not highly favored. Most parents who reported no information needs had received information either verbally or written; however, there was no difference whether the information was received only verbally or both verbally and written. Information needs were more often reported by parents with a migration background, with greater concerns about consequences of cancer and who had not received all the information before.

A major strength of this study is the population-based sample of parents of childhood cancer survivors with prospectively collected data on clinical variables from the Swiss Childhood Cancer

TABLE I. Characteristics of the Study Population, Comparing Participants and Non-Participants

	Participants		Non-participants[a]		
	N	%[c]	N	%[c]	*P*-value[b]
Total	189	100	117	100	
Sociodemographic characteristics of parent responder					
Sex					
Female	160	84.7	n.a.[d]		
Male	29	15.3	n.a.		
Age at study					
≤45 years	89	47.1	n.a.		
>45years	92	48.7	n.a.		
unknown	8	4.2	n.a.		
Migration background					
Swiss	172	91.0	n.a.		
Immigrant	17	9.0	n.a.		
Language region					0.516
German	132	70.2	78	66.7	
French	56	29.8	39	33.3	
Education					
Primary	101	54.3	n.a.		
Secondary	62	33.3	n.a.		
Tertiary	23	12.4	n.a.		
Employment					
Employed	150	79.4	n.a.		
Unemployed	39	20.6	n.a.		
Clinical characteristics of the child					
Diagnosis					0.511
Leukemia	74	39.2	46	39.3	
Lymphomas	16	8.5	10	8.5	
CNS tumors	34	18.0	23	19.7	
Neuroblastoma	13	6.9	8	6.8	
Retinoblastoma	13	6.9	5	4.3	
Renal tumors	12	6.3	8	6.8	
Hepatic tumors	4	2.1	3	2.6	
Malignant tumors	2	1.1	3	2.6	
Soft tissue sarcomas	14	7.4	3	2.6	
Germ cell tumors	2	1.1	3	2.6	
LCH	2	1.1	3	2.6	
Other[e]	3	1.6	0	0.0	
Treatment received[f]					0.793
Surgery only	30	16.0	20	17.5	
Chemotherapy	118	63.1	74	64.9	
Radiotherapy	30	16.0	17	14.9	
SCT	9	4.9	3	2.6	
Type of treating hospital					0.541
University hospital	160	84.7	102	87.2	
Regional hospital	29	15.3	15	12.8	
Child's age at diagnosis					0.831
0-1 years	58	30.7	35	29.9	
2-4 years	82	43.4	48	41.0	
5+ years	49	25.9	34	29.1	
Time since diagnosis					0.803
5-10 years	64	33.9	38	32.5	
10+ years	125	66.1	79	67.5	
Relapse					1.000
No	168	88.9	104	88.9	
Yes	21	11.1	13	11.1	
Parent-reported late effects					0.103
No	100	54.4	68	64.2	
Yes	84	45.6	38	35.8	
Parents involvement in follow-up care					
No	40	78.3	n.a.		
Yes	144	21.7	n.a.		

TABLE I. (*Continued*)

	Participants		Non-participants[a]		
	N	%[c]	N	%[c]	*P*-value[b]
Concerns about consequences of cancer					
No concerns	51	27.4	n.a.		
Medium concerns	55	29.4	n.a.		
High concerns	81	43.3	n.a.		

	Participants		Non-participants[a]		
	Mean	SD	Mean	SD	*P*-value[g]
Parent's age	46.1	4.8	n.a.		
Child's age at study	14.7	1.8	15.0	1.9	0.223
Child's age at diagnosis	3.4	2.2	3.6	2.4	0.573
Time since diagnosis	11.3	2.5	11.4	2.5	0.708

Percentages are based upon available data for each variable. CNS, central nervous system; LCH, Langerhans cell histiocytosis, SCT, stem cell transplantation; n.a., not applicable. [a]Non-participants include: parents who did not respond (n = 92), with unknown address (n = 22) or who refused to participate (n = 3) (Supplemental Figure 2). [b]*P*-value calculated from Chi-square statistics comparing parent participants and parent non-participants. [c]Column percentages are given. [d]Information was not available from non-participants. [e]Other: malignant epithelial neoplasms, malignant melanomas and other or unspecified malignant neoplasms. [f]Chemotherapy may include surgery, radiotherapy may include chemotherapy and/or surgery. [g]*P*-value calculated from paired t-test.

Registry and data from the follow-up questionnaires from the Swiss Childhood Cancer Survivor Study. Furthermore, the response rate was good (67%). A limitation might be self-selection because parents of specific groups may have been more reluctant to complete the questionnaire, especially after having filled in the baseline questionnaire. Other parents might have been excluded because they were not interested in the baseline questionnaire. Another limitation might be that only one parent was contacted and therefore only one questionnaire was filled in per family. Answers might differ between fathers and mothers and it is not known if questionnaires were completed together or alone. When assessing the information a person reported to have received, we have to take into account that the person might have received it, but did not understand it, forgot it or that the information might not have been given to the parents but to the survivors themselves even though they were quite young at diagnosis. In addition, the need for more information differs from person to person and this subjective need may influence our results. Due to the sample size, only a few results were statistically significant and therefore no subgroup analysis could be performed.

Until now little research has been done in the area of information needs of parents of long-term childhood cancer survivors. Therefore, we found relatively few studies addressing information needs of parents. Our findings about the domain and format of information needs are in line with those reported in a semi-structured telephone interview in Australia [8]. They reported that parents had information needs especially on fertility and post-treatment challenges and the desire to receive the information in a written format, like an information booklet. Other studies assessed needs in a broader way and found that information need was the most prevalent unmet need [19,20].

In our study, we showed that most parents remember they received some information, but that there is considerable room for improvement. The majority of parents received verbal information,

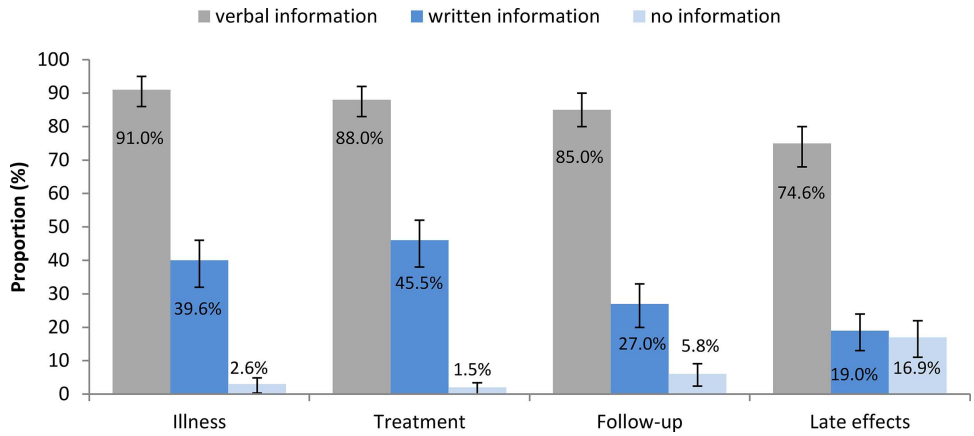

Figure 1. Overview of parents reporting to have received information on illness, treatment, follow-up and late effects by format (verbal, written, no information). Numbers do not add up to 100% because parents could indicate to have received both, verbal and written information. 95% confidence interval, calculated for binomial distribution.

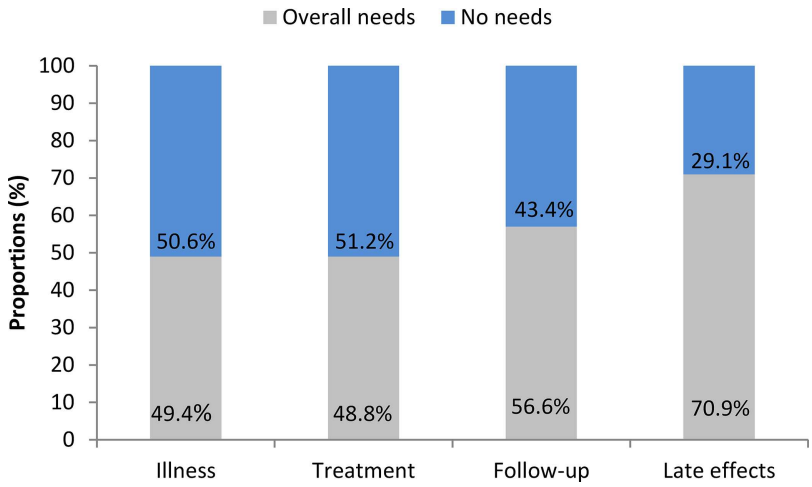

Figure 2. Proportion of parents who reported information needs versus no needs in the domains illness, treatment, follow-up and late effects.

a format that has its difficulties. It is good to get individual explanations by the doctor and to clarify ambiguities. But the information might be forgotten within a short time and not remembered long after the cure of the child [21]. This might explain the need of many parents to receive written general information in addition to verbal information. However also having received written information does not remove the need for additional information at a later stage.

It is surprising that today only a minority of parents would like to find more information on the internet. The cause might be the unreliable and impersonal character of information provided online. However, next to verbal and written information given by doctors this will probably be the format chosen in the future because of its accessibility, lower costs and broad availability. One study showed that there is a paucity of high-quality internet information with many sites lacking information on late effects [22]. Therefore, professionals caring for survivors and their parents should develop official online platforms with credible high quality health information, supplying targeted, detailed and trustable information regarding follow-up care and late effects.

We can assume that every parent receives information on illness and specific treatment by the doctor. A large proportion of parents reported never having received information on follow-up and especially on late effects, and more than half of the parents reported information needs in those two domains. This may be because at the time of diagnosis this information was not considered of importance or because parents really did not receive the information by the health care provider. This might become a problem in the future because every survivor and ideally also their parents should be aware of potential late effects. For many, regular follow-up to prevent, screen, detect and treat health care problems at an early stage is of great importance. The unawareness both of survivors and parents might partly explain the high number of patients being lost to follow-up in adulthood [23].

Increased needs were reported by parents with a migration background, with greater concerns about consequences of cancer and by parents who did not receive all the information. Not statistically significant but potentially relevant is a trend for higher information needs among parents with higher education. It is interesting that both parents with higher education and parents with

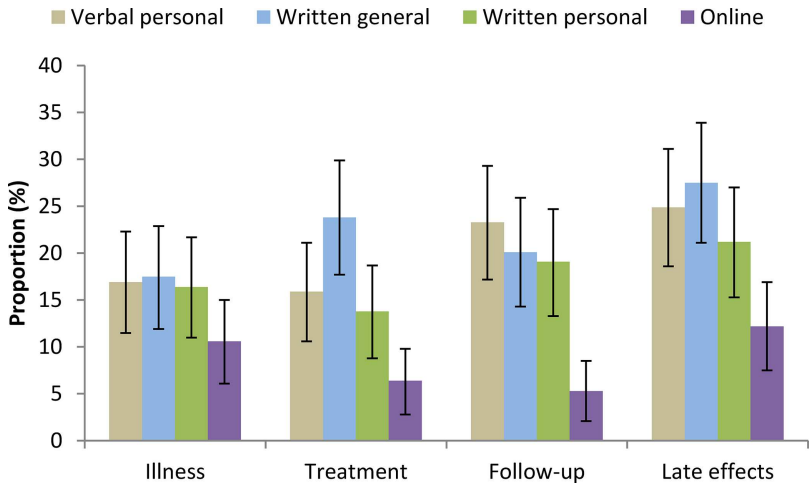

Figure 3. Preferred format of information which parents with information needs would like to receive on illness, treatment, follow-up and late effects. CI 95% confidence interval.

TABLE II. Factors Associated With Information Needs in Parents (From Univariable Logistic Regression Models)

		Information needs present		Associations with information needs		
	N Total	N	(%)[a]	OR	95%CI	Global *P*
Sex						0.985
Female	151	113	74.8	1		
Male	28	21	75.0	1.01	0.39–2.55	
Age at study						0.477
≤45 years	84	61	72.6	1		
>45 years	87	67	77.0	1.26	0.63–2.52	
unknown	8	6	75.0	1.13	0.21–6.01	
Migration background						**0.039**
Swiss	163	119	73.0	1		
Immigrant	16	15	93.8	5.55	0.71–43.2	
Language region						0.199
German	127	99	77.9	1		
French	51	35	68.6	0.61	0.29– 1.27	
Education						0.298
Primary	96	73	76.0	1		
Secondary	59	41	69.5	0.71	0.35–1.48	
Tertiary	21	18	85.7	1.89	0.51–6.99	
Employment						0.648
Employed	143	106	74.1	1		
Unemployed	36	28	77.8	0.54	0.51–2.92	
Diagnosis						0.359
Leukemia/Lymphoma	84	59	70.2	1		
CNS tumor	33	27	81.8	1.91	0.70–5.19	
Other tumor[b]	62	48	77.4	1.45	0.68–3.10	
Treatment received[c]						0.413
Surgery	28	19	67.9	1		
Chemotherapy	112	82	73.2	1.29	0.53–3.17	
Radiotherapy	28	24	85.7	1.92	0.76–10.67	
SCT	9	7	77.8	1.49	0.29–9.64	
Type of treating hospital						0.701
University hospital	152	113	74.3	1		
Regional hospital	27	21	77.8	1.21	0.45–3.21	
Child's age at diagnosis						0.481
0–1 years	55	44	80.0	1		
2–4 years	79	56	70.9	0.61	0.27–1.38	
5+ years	45	34	75.6	0.77	0.30–1.90	
Time since diagnosis						0.626
10+ years	118	87	73.7	1		
<10 years	61	47	77.0	1.19	0.58–2.47	
Relapse						0.565
No	159	118	74.2	1		
Yes	20	16	80.0	1.38	0.44–4.40	
Parent-reported late effects						0.338
No	92	66	71.7	1		
Yes	82	64	78.1	1.40	0.70–2.79	
Parents involvement in follow-up care						0.089
No	38	24	63.2	1		
Yes	136	105	77.2	1.98	0.91–4.27	
Concerns about consequences of cancer						**0.024**
No concerns	48	29	60.4	1		
Medium concerns	53	42	79.3	2.50	1.04–6.04	
High concerns	77	63	81.8	2.95	1.30–6.68	
Information received[d]						**0.035**
Yes	138	100	72.5	1		
No	35	31	88.6	2.95	0.97–8.90	

Percentages are based upon available data for each variable. CI, confidence interval; CNS, central nervous system; SCT, stem cell transplantation; bold, *P* value lower than 0.05 [a]Row percentages are given. [b]Other: malignant epithelial neoplasms, malignant melanomas and other or unspecified malignant neoplasms. [c]Chemotherapy may include surgery, radiotherapy may include chemotherapy and/or surgery. [d]Information received means parents perception of information received.

a migration background have more information needs [24]. Having a higher education probably means being more likely to understand and process the information and therefore try to seek additional information. In contrast, parents with a migration background, probably due to language difficulties or lack of familiarity with the health system, might have larger problems in understanding the information given and therefore report a higher information need.

Even though not statistically significant, our results suggest that parents of children with a more severe disease (CNS tumor, relapse, radiotherapy, late effects) may have a higher need for information. The complexity of the disease together with often disabling late effects might leave parents with many open questions. Information provision to parents should be improved because of parents' crucial role in transferring this information to their children once they take over responsibility for their own health. Only if information needs are met and information is understood, will parents be able to point out the importance of continued medical care and to prevent their child from becoming lost to follow-up. Informed parents can also be more active towards health care providers and this may help to further motivate their child to adhere to follow-up and live a healthy lifestyle. Additionally, information should be provided to survivors themselves repeatedly during follow-up care in an age-adapted way.

Information to parents is not only important because of knowledge transfer, but also to reassure themselves and to reduce insecurity by giving adequate and consistent information throughout, and long after treatment [4]. There remains an open question about who should provide information, in which format and at which time point [25]. Just because parents receive written information on diagnosis does not necessarily mean they do not have information needs many years later. Given the rapid increase in the number of long-term survivors, health care providers are progressively lacking resources to continue high quality follow-up care for long-term survivors. We therefore suggest the use of a survivorship passport including information about diagnosis, treatment and expected late effects as well as a personal follow-up care plan and information on health behaviors [26]. Such a passport is currently being developed by the European ENCCA project [27]. Another passport has been developed by the Children's Oncology Group and is already in use in many institutions [28]. A summary of disease and treatment together with an individualized survivorship care plan will help parents and eventually survivors to get the needed information on their past and future.

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